



# Impact of JM on Mental Health

---

2018 Update on Juvenile Myositis Care and Research

Andrea Knight, MD, MSCE

June 30, 2018



# Disclosures

---

I have no relevant financial relationships to disclose.

# Goals:

---

1. Describe importance of emotional health for patients with JM
2. Discuss disease-related factors affecting emotional health
3. Identify ways to improve emotional health for patients with JM



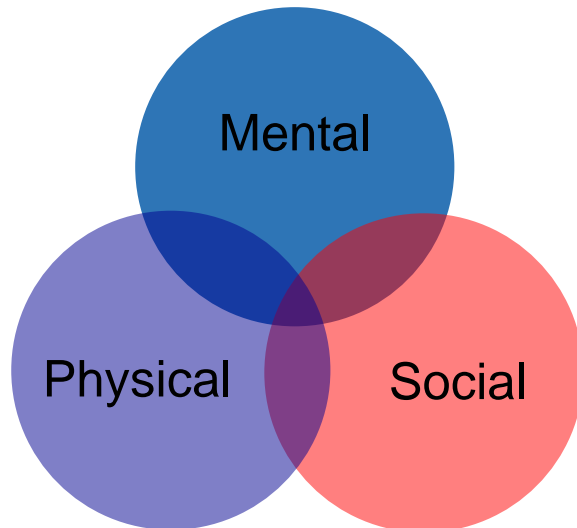
# Emotional health – critical for patients

---



“...essential to a person’s well-being, healthy family and interpersonal relationships, and the ability to live a full and productive life”

*Healthy People 2020, US Department of Health & Human Services*



“Mental health disorders have a serious impact on physical health and are associated with the prevalence, progression, and outcome of some of today’s most pressing chronic diseases.”

*Healthy People 2020, US Department of Health & Human Services*

# Juvenile Myositis (JM) – a challenging disease

---

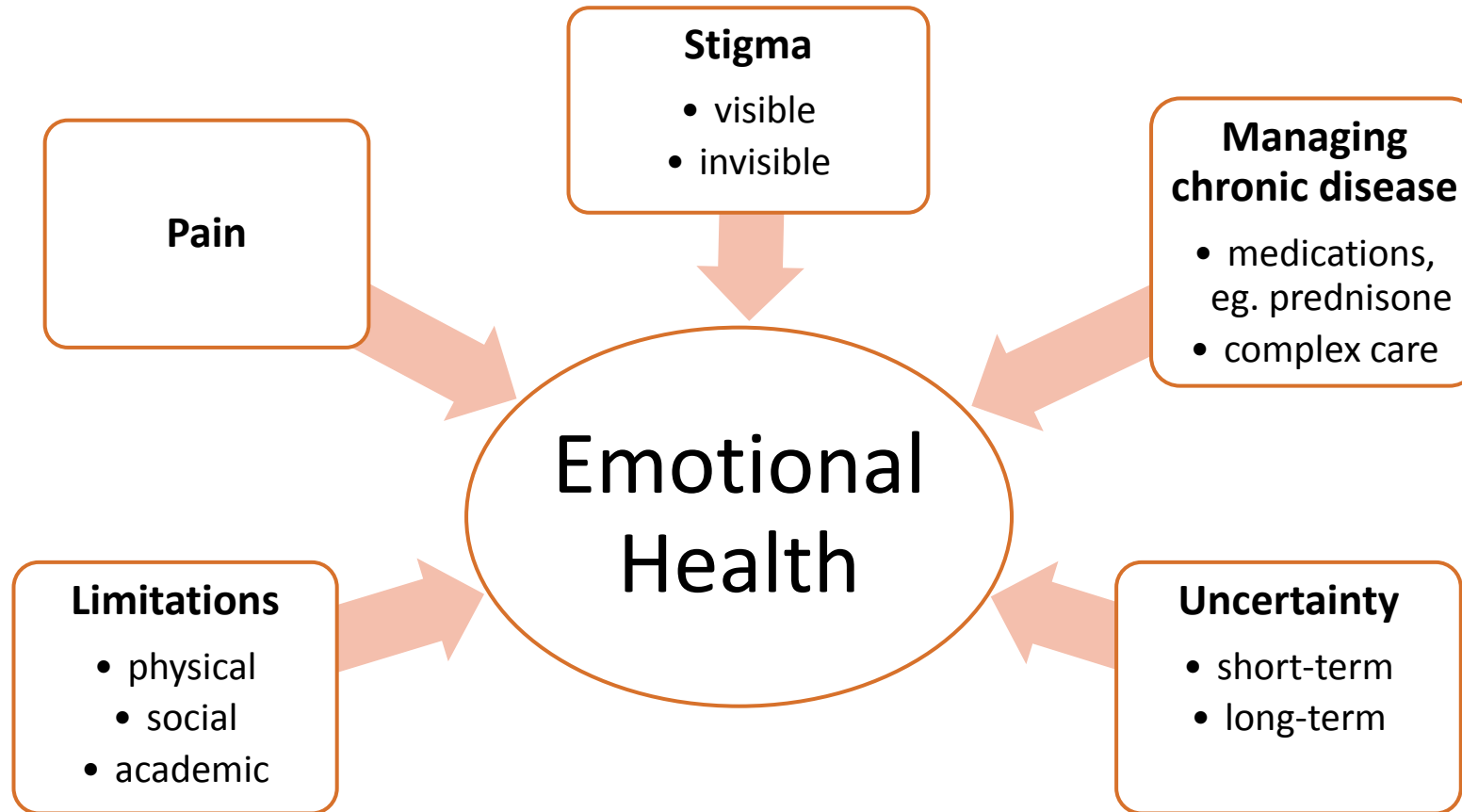
- inflammatory disease involving muscle and skin
- muscle weakness and pain → physical limitation
- skin rashes



- chronic, requires ongoing treatment and medical care

# Emotional health & dealing with JM

---



# Emotional health problems in youth with JM

---

- **1 in 3** with depression symptoms



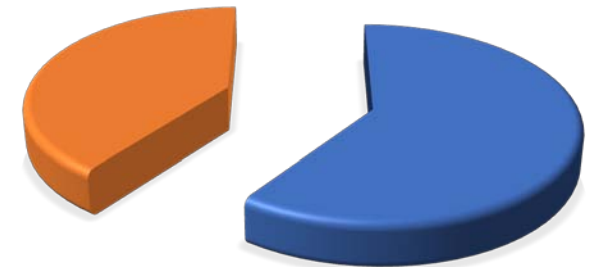
- **1 in 2** with anxiety symptoms



- **1 in 4** with difficulty coping with /adjusting to illness

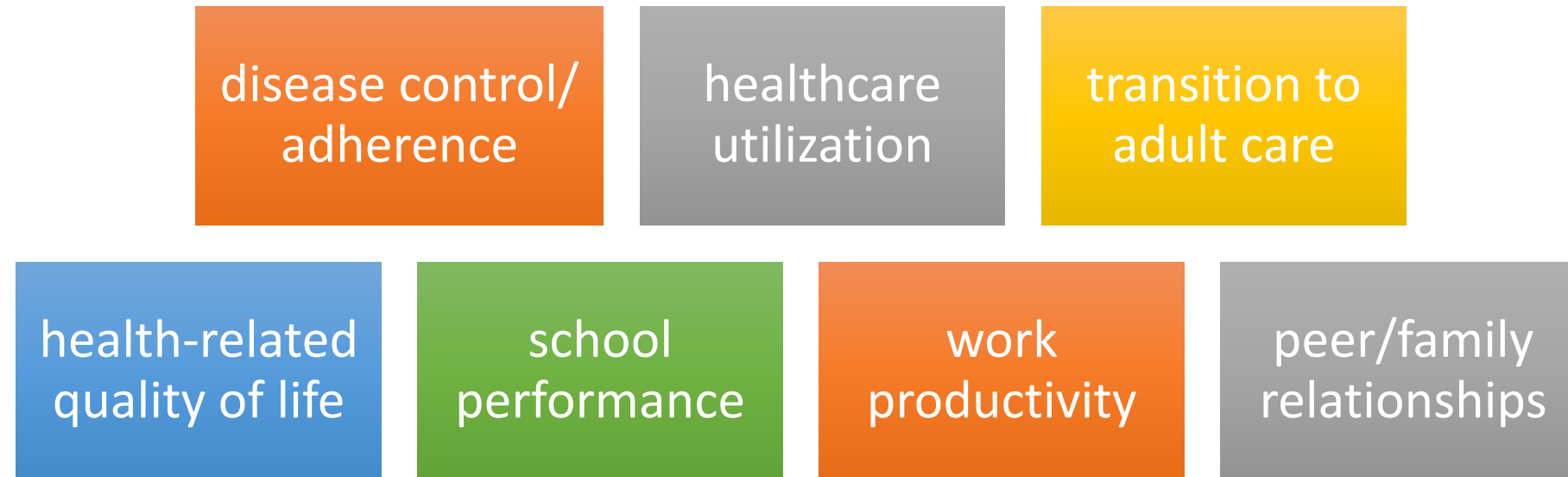


- **40 %** of these symptoms not brought to medical attention



# Impact of emotional health on outcomes

---





# Improving emotional health for patients with JM

---

Education about emotional health for patients, parents and families

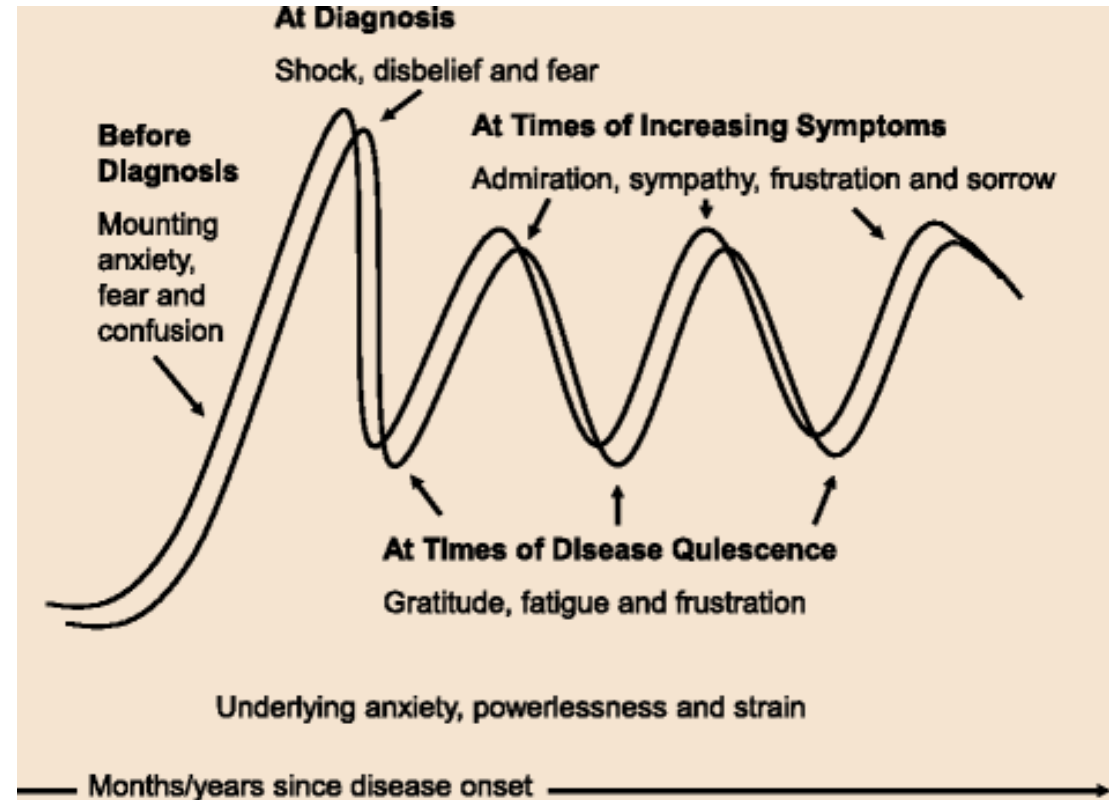
Identification of patients (and family members) with emotional health challenges

Intervention for emotional health problems

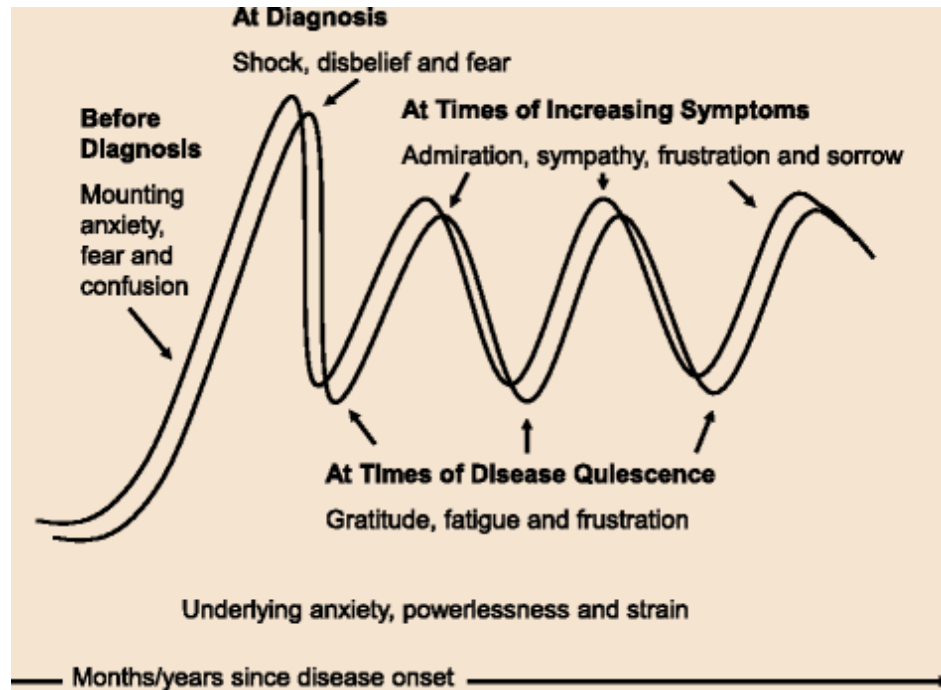


# Acknowledging the emotional roller coaster...

---



# Emotional health education – early & ongoing



- benefits for patients, parents & siblings
- increase mental health awareness to address problems early
- *normalize* mental health as part of overall care -> reduce stigma, fear

# Identifying emotional health problems early is key

---

Early identification of depression symptoms in kids  
= lower risk of major depression & suicide as adults



American Academy  
of Pediatrics

- recommends depression screening for adolescents & young adults ages 11-21 years
  - targeted to primary care settings
  - no specific recommendations for anxiety
  - does not address caregiver/family issues

# Emotional health screening in rheumatology

---

*“We actually consider her  
rheumatologist  
her primary caregiver”*  
—  
*Mother of 15 y/o girl with lupus*

- efforts underway to start routinely screening patients for depression & anxiety in pediatric rheumatology clinics
- additional screening needs identified:
  - coping/adjustment to illness for patients/parents/families
  - emotional needs for transition to adult care



# Emotional health intervention approaches

---



## Psychosocial support staff in rheumatology clinics

- social workers & psychologists



## Mental health professionals in your community

- therapists, psychologists, psychiatrists, adolescent medicine & primary care doctors



## Peer support networks

- for patients, parents, families

# Summary

---

- Youth with juvenile myositis are at risk for emotional health problems
- Emotional health problems can negatively impact physical and social well-being
- Education about emotional health is key for patients and families to recognize and address emotional health challenges
- Health providers can help recognize and address emotional health challenges
- Early intervention for emotional health problems can help provide the best outcomes



Children's Hospital  
of Philadelphia™

**PolicyLab**

Center for Pediatric Clinical Effectiveness

knightan@email.chop.edu



@PolicyLabCHOP